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## BEST PRACTICE

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### Special Needs Registries: Information Collection, Confidentiality, and Maintenance

#### PURPOSE

This Best Practice describes ways to collect, secure, and maintain information for special needs registries.

#### SUMMARY

The process of collecting, securing, and maintaining information is essential for special needs registries. Jurisdictions rely on information from registrants to gain a better understanding of the needs of their populations with functional needs and to facilitate planning efforts. In order to operate a registry effectively, jurisdictions must develop methods of soliciting information from individuals while ensuring that the information remains confidential, and keeping information as up-to-date as possible.

#### *About This Best Practice*

This Best Practice is part of the Special Needs Registries Best Practice Series. It provides information about issues that are important to consider in collecting, securing, and maintaining information for special needs registries. This Best Practice consists of the following sections:

- Information Collection
- Information Confidentiality
- Information Maintenance

#### DESCRIPTION

##### *Information Collection*

Jurisdictions can employ various methods to collect information from registrants. These methods include hard copy registration forms, registration over the telephone, electronic registration forms, or secure Web portals. Jurisdictions must determine which information collection methods are most effective for the populations served by the registry and can make registration convenient for individuals by providing several different registration options. This makes it more likely that individuals can use the registration method that matches their capabilities and needs available to them.

##### **Hard Copy Registration Form**

A hard copy registration form is the most prevalent registration method used by jurisdictions. Individuals or agencies that represent or care for individuals complete these forms and return them by mail, by fax, or by delivering it to a designated location. Hard copy registration forms have several benefits. When they are made available in public locations, they serve as a way to promote the registry. They are also useful for individuals

who lack a computer or Internet access. Further, jurisdictions can opt to keep hard copy forms in a secured location to serve as a backup registry.

However, there are several drawbacks to using hard copy registration forms. Jurisdictions that utilize these forms often have to manually enter the registrant's information into the registry. This can be a time-consuming process. Also, transposing information from registration forms to the registry leaves room for error. Unclear handwriting from registrants can also be problematic. This is especially true for information like medications that may be misinterpreted by non-medically trained personnel or volunteers. Finally, individuals may be unable to complete hard copy registration forms without assistance, which could be a deterrent against participating in the registry.

Jurisdictions can make hard copy registration forms available at certain public locations, such as libraries, churches, or senior citizens clubs, or at service organizations like the Lion's Club or Kiwanis. Often, various agencies and organizations, such as home health care providers and public health departments, distribute the forms to registry-eligible clients. Many jurisdictions provide a phone number or email address on their promotional materials or on their Web sites that individuals can use to request registration forms.

### Telephone Registration

Several jurisdictions allow individuals to register by telephone. These jurisdictions provide designated phone numbers or arrange for registration through an information phone service, such as 2-1-1. For example, Monroe County, Florida, Social Services provides a telephone number that individuals can contact to register. Monroe County accepts registrations from individuals during emergencies but requires those individuals to complete forms at a later date. In addition, Utah informs individuals that registration for the state registry can be completed by dialing 2-1-1.

2-1-1 is a telephone number that provides information about critical health and human services available in the local community.

Telephone registration is helpful for individuals who are unable to obtain assistance with completing a hard copy or electronic registration form; however, registration by phone can be time-consuming for the staff member or volunteer collecting information from the individual. Also, the process of transcribing an individual's information leaves room for error.

### Electronic Registration Form

Several jurisdictions provide their registration form in portable document format (PDF) or other electronic format online, usually on the jurisdiction's Web site. These electronic forms can be printed, completed by hand, and either mailed, faxed, or delivered to a designated location. Some jurisdictions offer the option of completing the form electronically.

**Client Information** \*Required field - Please fill in a valid value for all required fields

Please do not use special characters when entering the below information. (ex: ' & %)

\*Email Address:   
If you do not have an email address, enter 'N/A' in this field.

\*First Name:

\*Last Name:

\*Home Phone:  \*Cell Phone:   
You must provide either your home phone number or your cell phone number. Both fields can not be blank.

\*Street Address:   
Only Jefferson Parish residents can apply for the Jefferson Parish Assisted Evacuation Assessment Registry.

\*City:  \*Zip:

\*Do you require the use of a TDD/TTY?: ☐ Yes ☐ No

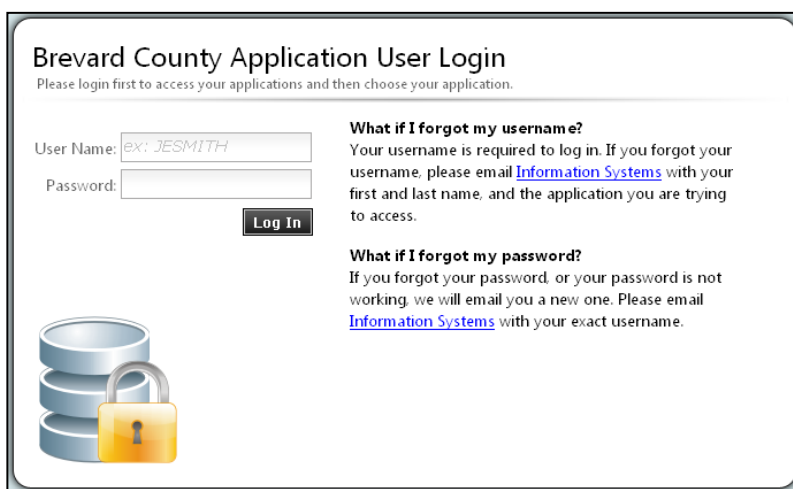
**Jefferson Parish, Louisiana, secure Web portal registration**

Registrants can then complete the form on the computer, print the completed form, and mail, fax, or deliver the form to the appropriate location. Jurisdictions can also provide registrants with the option of emailing their completed forms. Lee County, Florida, Emergency Management's Special Needs Program and the Jackson and Josephine Counties, Oregon, Disaster Registry application forms contain links that registrants can select to email their completed forms to the registries.

An electronic registration form is convenient for individuals with computer access. Some registries have the capacity to input information from electronic registration forms directly into the registry, saving time and ensuring the information is entered into the registry accurately. Additionally, electronic forms are always legible. However, it is important to supplement electronic forms with other registration methods, such as hard copy registration forms, to serve individuals who lack Internet or computer access.

### Secure Web Portal Registration

Some registries offer registration through secure Web portals. Registrants enter information into designated fields, and the information is submitted directly to the registry. Often, secure Web portals allow registrants to create profiles with user names and passwords that they can then access later to update their information. Jefferson Parish, Louisiana, Pinellas County, Florida, and Delaware County, Ohio, offer this capability on their special needs registries.



**Brevard County, Florida, Emergency Management's Special Needs Program login**

Secure Web portals are beneficial for several reasons. Registrants input their information directly into the registry, which saves time and ensures that information is entered into the registry accurately. Additionally, registrants can easily update their information at any time using their user names and passwords. This method of registration is particularly useful for organizations like home health care agencies that often need to register several individuals. However, registration through a secure Web portal is limited to those with access to the Internet and requires either computer proficiency or assistance from someone who is computer proficient.

### Required Signatures

Jurisdictions must determine if they require signatures from their registrants and, if so, which form of registration best meets this need. Jurisdictions may require signatures so that registrants can confirm their understanding of registry procedures and policies. Some registries only accept hard copy registration forms in order to collect signatures from registrants. The Orange County, North Carolina, Department of Social Services' Special Needs Registry requires that its applicants sign a hard copy registration form to acknowledge that they have read and accepted the Health Insurance Portability and Accountability Act notification provided on the form. Similarly, Monroe County, Florida,

requires that applicants sign forms to indicate that they understand the implications of participating in the registry and how their information will be used during an emergency.

Jurisdictions that allow online or electronic registration can obtain signatures electronically from individuals. This is done by providing space for registrants to type in information such as their name and date at the bottom of the registration form, similar to a signature line for a hard copy registration form. For example, Pinellas County, Florida, Emergency Management's Special Needs Registry requires registrants to type in their email address and the date at the bottom of the registration form, authorizing the release of their information to emergency management and public health officials. Jurisdictions can also provide consent and authorization language at the bottom of the registration form and inform registrants that they are agreeing to the stipulations in this language by submitting their registration form. For example, Jefferson Parish includes a "Submission Notice" at the bottom of its registration form that registrants consent to by clicking the "Submit Registration" link.

### **Confirming Information**

Jurisdictions should take steps to ensure that the information provided to them is accurate. Jurisdictions approach this task in various ways. Delaware County, Ohio, sends a liaison to the registrant's residence. The liaison collects information from the individual and also provides the individual with information about personal preparedness. When individuals register for the Fairfax County, Virginia, Office of Emergency Management's Special Needs Registry, their information is not entered into the registry until Fairfax County Office of Emergency Management personnel review the information and contact the individual to confirm their information.

Jurisdictions should also develop processes to ensure that applicants are eligible for the registry and, if they are, to determine which services they require. Several registries submit registration information to hospitals or health departments who can then determine the type of assistance or shelter the registrant requires. Personnel at Bradford County, Florida, Emergency Management's Special Needs Registry and the Monroe County, Florida, Special Needs Registry contact their health departments or local health provider if there is uncertainty about what type of sheltering or transportation a registered individual requires. In Pinellas County, Florida, the health department must review all applications before individuals can be assigned to a special needs shelter. Similarly, the medical director of the Lee County, Florida, Department of Health is responsible for assigning individuals to shelters from the county's registry.

### **Information Confidentiality**

Jurisdictions must have procedures in place to secure the confidential background and medical information that registrants submit for participation in the registry. Federal and state guidance emphasizes the importance of ensuring that registrants' information is shared only with emergency management personnel on a strict need-to-know basis. This guidance also stipulates that registrants' information should be used only for emergency assistance.

See [New Hampshire State Emergency Operations Plan Support Annex: Functional Needs Guidance \(Version 3.0\)](#), Appendix 4, for more registry guidance.

### **Access to Information**

Jurisdictions must take steps to control who has access to special needs registry information. Several jurisdictions limit registry access to only one or two staff members. For example, access to Jackson County, Wisconsin, Emergency Management's

See DHS's [Individuals with Disabilities in Emergency Preparedness Annual Report 2005](#) for more registry guidance.

Disaster Registry is limited to the Jackson County Emergency Management Department's director and one staff member. If registry access is limited to very few individuals, jurisdictions must have procedures in place to grant access to additional staff in the event that the regular staff members are not available during an emergency. For example, personnel at Bradford County, Florida, Emergency Management's Special Needs Registry store passwords for the registry in a secured location for use during emergencies.

However, some registries share registry information with personnel at partner organizations, such as hospitals or departments of health and social services, for assistance with registry operations. For example, in Pinellas County, Florida, the county health department must review an individual's registry application before he or she is assigned to a shelter. Similarly, personnel who operate Monroe County, Florida, Social Service's Special Needs Registry consult the county health department or other local health provider if there is uncertainty surrounding whether a registrant will need ambulance transport during an emergency. During a sheltering event, Monroe County personnel provide the county department of health with a copy of the registry on a thumb drive. The thumb drive is not populated until the event has commenced, and at the conclusion of the event, the department of health returns the thumb drive to the registry.

### **Emergency Dispatch**

Some jurisdictions opt to share their registry's information with emergency dispatchers to assist emergency responders outside of large-scale disasters. Dispatchers may collect information about registrants during emergency responses; however, dispatchers are not allowed to provide this information to registries or others since the information dispatchers collect is considered confidential medical information.

### **Additional Security Measures**

Jurisdictions must take the necessary precautions to secure the information in their registries. The steps jurisdictions take to maintain the security of their registrants' information vary widely. For example, jurisdictions can store their registries on password protected servers, restrict access using software permissions and controls, use a Hypertext Transfer Protocol Security (HTTPS) connection for the registry Web site, or protect the physical location of the registry using access cards. Santa Clarita, California, assigns personnel passwords that allow varying levels of access to its registry. This allows multiple people to use the registry, but limits what each person can access on a need-to-know basis. Santa Clarita can also track which personnel have accessed the registry. Pinellas County, Florida, assigns its registrants numbers that are used instead of their names in communication among personnel to maintain registrant confidentiality.

### **Information Maintenance**

The information contained in special needs registries must be kept up-to-date. Incorrect information in the registry could slow response or evacuation operations. Maintenance of the information in the registry is often the biggest challenge jurisdictions face. Registrants move, their health status changes, or they may recover from the condition that made them eligible for the registry. Jurisdictions must ensure that they have a process in place for updating registrants' information.

Federal Emergency Management Agency (FEMA) guidance recommends that jurisdictions update the information on their registries annually; however, several jurisdictions undertake this process as often as quarterly. Jurisdictions solicit updated information from registrants in a variety of ways depending on

See FEMA's [Interim Emergency Management Planning Guide for Special Needs Populations](#), Appendix E, for more registry guidance.

the number of registrants and the system platform. They can contact registrants by using mail, the telephone, or electronic notifications to remind them to update their information. However, jurisdictions must determine what actions to take when they are unable to reach registrants.

### **Reminders Through the Mail**

Many registries send information update requests to registrants by mail. For example, personnel at the Dane County, Wisconsin, Emergency Management's Disaster Assistance Voluntary Registry send out two mailings annually to its registrants instructing them to update their information. Similarly, Pinellas County, Florida, sends out letters annually to registrants and experiences a 60–70% response rate to these letters. This is an effective method for quickly reaching a large number of registrants; however, this can be problematic if registrants have moved. Also, registrants may not be as motivated to act as a result of a mailing as they would from more direct communication.

### **Telephone Reminders**

Some registries contact each registrant by phone to solicit information updates. If the registrant cannot be reached, the emergency contact is called. This method is thorough and allows for immediate communication with registrants. Jurisdictions can use telephone calls to remind the registrant to update his or her information or to collect updated information at the time of the call. However, this process can be very time-consuming and resource-dependent, often requiring the assistance of volunteers. This method may not be suitable for large registries. For example, personnel at the Buncombe County, North Carolina, Emergency Services' Special Needs Registry enlist volunteers to call registrants annually to ask if they need to update their information. If registrants need to update their information, volunteers mail them a form that the registrants can complete and return to the emergency services department. The volunteers reach out to the registrant's emergency contact if they are unable to reach the registrant. In addition, Jackson and Josephine Counties, Oregon, Disaster Registry volunteers call registrants quarterly to solicit information updates.

### **Electronic Notifications**

Registries with secure Web portals can send notifications electronically to users to remind them to update their user profiles. Registrants can then log in to their user profiles to make the necessary changes. For example, personnel at Mifflin County, Pennsylvania, Public Safety's Special Needs Registry send an electronic reminder to its registrants 1 year after they register. The county issues registrants a user name and password to log into the registry and update their information. Delaware County, Ohio, sends an email manually to registrants every 6 months reminding them to log in to their accounts and update their information. If the registrant fails to update his or her information within 10 days, the registry sends an alert to registry personnel, who then send a representative to the registrant's residence.

Electronic notifications are a quick, easy method for registrants to update their information; however, this method requires that registrants have access to email accounts. Often, registrants rely on a caregiver or family member to assist them with updating their registry information electronically.

### **Partnerships**

Some jurisdictions rely on partnerships with organizations that work with special needs populations to ensure that the information on their registries is up-to-date. Jurisdictions communicate with these organizations on a regular basis to solicit information updates for the organizations' clients who participate in the registry. For example, Jackson County, Wisconsin, Special Needs Registry personnel interact closely with public health and home



health organizations. As a result of this interaction, information updates about the organizations' clients are communicated as they occur. Jackson County has been so successful with this approach that annual updates are no longer a challenge because information is updated continuously throughout the year.

For more information about partnerships between special needs registries and organizations, see the *Lessons Learned Information Sharing (LLIS.gov)* Lesson Learned, [Disaster Assistance Registries: Conducting Outreach Through Trusted Organizations](#).

### **Procedures for Managing Unresponsive Registrants**

Jurisdictions should have procedures in place in the event that registrants do not respond to requests to update their information. Many registries remove registrants after several failed attempts at contacting the registrant. The Denver 911 Emergency Communications' Special Needs Registry automatically purges registrants if they have not reregistered within 1 year of their original registration. Registrants are removed from the Dane County, Wisconsin, Emergency Management's Disaster Assistance Voluntary Registry if they do not respond to letters informing them to update their information. The Jefferson Parish, Louisiana, Assisted Evacuation Assessment Registry roster is recreated every year, so registrants must reregister every year if they wish to remain on the registry.

In Monroe County, Florida, personnel who operate the special needs registry contact all registrants annually by phone to reregister. If a registrant cannot be reached, personnel attempt to contact the client again several days later. If the registrant and his or her emergency contact still cannot be reached, personnel send a letter to the resident's address. If applicable, personnel also contact the last known agency or organization with which the registrant was associated. If no additional information can be gathered, the registrant's information remains in the registry database, but he or she is removed from the active part of the registry.

### **Backup Copy**

Many special needs registries are maintained in an electronic format such as in a Microsoft® Access® database, Microsoft® Excel® spreadsheet, or registry-specific software. Jurisdictions must have methods of accessing registry information if electricity or Internet connections fail. Jurisdictions can choose to back up their registries either electronically or in hard copy. For example, some jurisdictions choose to save a static copy of the registry on a staff member's hard drive. Other jurisdictions, such as Bradford County, Florida, and Santa Clarita, California, keep paper copies of their registries in secured locations should computer access become unavailable.

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Salley, Mack. Deputy Fire Marshal, Buncombe County, North Carolina, Emergency Services Department. Interview with *Lessons Learned Information Sharing*, 19 Aug 2010.

Steinhauer, Michael. Special Needs Planner, Dane County, Wisconsin, Department of Emergency Management. Interview with *Lessons Learned Information Sharing*, 18 Aug 2010.

### **Links**

Bradford County, Florida, Emergency Management, Special Needs Shelter Registry.

<http://www.bradford-co-fla.org/Emergency%20Man/emSpecialNeeds.html>

Brevard County, Florida, Emergency Management, Special Needs Program.

[http://embrevard.com/special\\_needs.cfm](http://embrevard.com/special_needs.cfm)

Buncombe County, North Carolina, Emergency Services, Special Needs Registry.

<http://www.buncombecounty.org/governing/depts/es/>

Dane County, Wisconsin, Emergency Management, Disaster Assistance Voluntary Registry.

<http://www.countyofdane.com/emergency/needs/registry.aspx>

Delaware County, Ohio, Special Needs Registry.

<http://www.delcospecialneeds.com/>



Denver 911 Emergency Communications, Special Needs Registry.

<http://www.denvergov.org/911SpecialNeedsRegistry/tabid/424814/Default.aspx>

Fairfax County, Virginia, Office of Emergency Management, Special Needs Registry.

<http://www.fairfaxcounty.gov/specialneeds/>

Jackson and Josephine Counties, Oregon, Disaster Registry.

<http://www.co.josephine.or.us/page.asp?navid=519>

Jefferson Parish, Louisiana, Assisted Evacuation Assessment Registry.

<http://jp-appserver.jeffparish.net/webapps/EOCAssessReg/DEFAULT.asp>

Lee County, Florida, Emergency Management, Special Needs Program.

<http://www.leeec.com/shelterevacuation/Pages/SpecialNeeds.aspx>

Mifflin County, Pennsylvania, Public Safety, Special Needs Registry.

<http://www.co.mifflin.pa.us/PublicSafety/Pages/SpecialNeeds.aspx>

Orange County, North Carolina, Department of Social Services, Special Needs Registry.

[http://www.co.orange.nc.us/socsvcs/special\\_needs\\_registry.asp](http://www.co.orange.nc.us/socsvcs/special_needs_registry.asp)

Pinellas County, Florida, Emergency Management, Evacuation Assistance Registry.

<http://www.pinellascounty.org/emergency/specialneeds.htm>

Santa Clarita, California, Special Needs Registry.

<http://www.santa-clarita.com/index.aspx?page=755>

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